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The novel use of life grids in a phenomenological study of family carers of people with Profound Intellectual and Multiple Disabilities and Dysphagia

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Abstract

Life grids have been used in qualitative studies for the last two decades. They provide an activity which researcher and participant can focus their attention on, help build rapport, and reduce the control the researcher may hold within a session. Here we describe the novel use of life grids at the end of a data collection phase. Used in this previously un-reported way life grids assisted the closure of the data collection phase by summarizing the data collection and marking departure from the field. Creation of a life grid produced a tangible outcome, evidencing the work undertaken within the data collection period. They served as a powerful member checking tool, allowing participants to make additions and corrections to the data. In this article the use of life grids in this novel way is described and recommended by the authors.

Introduction

People with Profound Intellectual and Multiple Disability (PIMD) are individual and unique. It is important that to understand and develop we understand the experiences of all members of the community in which we live. People with PIMD often struggle to tell their stories without support (Mitchell, Boettcher-Sheard, Duque & Lashewicz, 2017). They have disabilities which include profound cognitive impairment and may also include sensory impairment, physical disability, and a range of health problems that can include conditions such as autistic spectrum disorder and mental distress. Eating and drinking difficulties (dysphagia) are common in people with PIMD (National Patient Safety Agency, 2004). In order to make sure that individuals with dysphagia remain well-nourished and hydrated, long term management is often necessary. The way we eat and drink and what we like to eat and drink are extremely personal and differs among individuals and among families. In order to ensure that the support given to individuals and families is individualised and person centred it is important to understand each person's needs and preferences. However, evidence indicates that professionals' points and view and family points of view about eating and drinking differ, and this can result in challenging therapeutic relationships (Crawford & Leslie, 2007; Crawford & Leslie, 2012; Leslie & Crawford 2008; Leslie, Crawford, & Roe 2008,). As such, it is important to consider new and innovative ways of gathering and including family views. In this article we will describe the novel use of the life grids method and highlight its effectiveness in enabling family carers to share and summarize complex information at the end of qualitative data collection. This is in contrast to their use previously described in the literature, at the outset of data collection.

It is important to note that the children referred to in this study were all over 18 and as such, were adults. In terms of their relationship to the participants, their mothers, they were their children and are described as such in this article.

The study was given ethical approval, by NRES Committee North East - Newcastle and North Tyneside 2, by the University of Edinburgh and by the host NHS Foundation Trust. Participants provided full written consent.

Methodological underpinnings

In this study we investigated the lived experience of family carers of people with PIMD and dysphagia. In order to conduct such an investigation, because we explored experiences, interpretations and meaning, we were guided by a qualitative research model. We wanted to understand how the lived experience of PIMD, dysphagia and meaning making shapes families' beliefs, interactions and decision making in relation to eating and drinking.

The study aimed to explore how “the lived experience ...gives meaning to each individuals' perception of the particular phenomenon and thus presents to the individual what is true or real in his or her life” (Penner & Clement, 2008, p.93). Hewetson and Singh (2009) studied the lived experiences of mothers caring for a child with dysphagia. The aims of their study were to

describe a group of mothers' experiences in addressing the feeding needs of their children; explore how these mothers defined their role and identity as a mother; and report barriers to and enablers of capacity to provide home-based care and to access health care services (p. 323).

In a similar study Sleigh (2005) looked at the feeding experiences of mothers of children with Cerebral Palsy. She claimed

for the families feeding and concerns about the method of feeding affect many areas of their daily life but we know little about what the experience is actually like. [Her]

study aimed to explore mothers' experience of feeding children with cerebral palsy (p. 373).

These studies were supported by a phenomenological methodology.

Phenomenology is the study of phenomena as they are experienced by the individual, in the first person (Smith, Flowers, & Larkin, 2009). In phenomenological studies it is essential to look at the subjective experience of the individual and the meanings that have been created by the individual as a result of living through particular everyday events, however great or small (Penner & Clement, 2008). Their experience 'intends' towards the event or phenomenon. It is related to that phenomenon. The experience can't exist without the phenomenon. Smith (2013) describes how in phenomenology, following Husserl (1927), investigators are interested in experience, but it is always experience 'of' something, experience is directed, or 'intends' towards something, "everyday experience can be either first-order activity or second-order mental and affective responses to that activity – remembering, regretting, desiring , and so forth...we are concerned with examining subjective experience, but that is always subjective experience of 'something'" (p. 33). In this study we used semi structured interviews as the primary method for gathering data, and then life grids were a method we used to support our investigation of the subjective experience of food and mealtimes for family carers of people with PIMD and dysphagia.

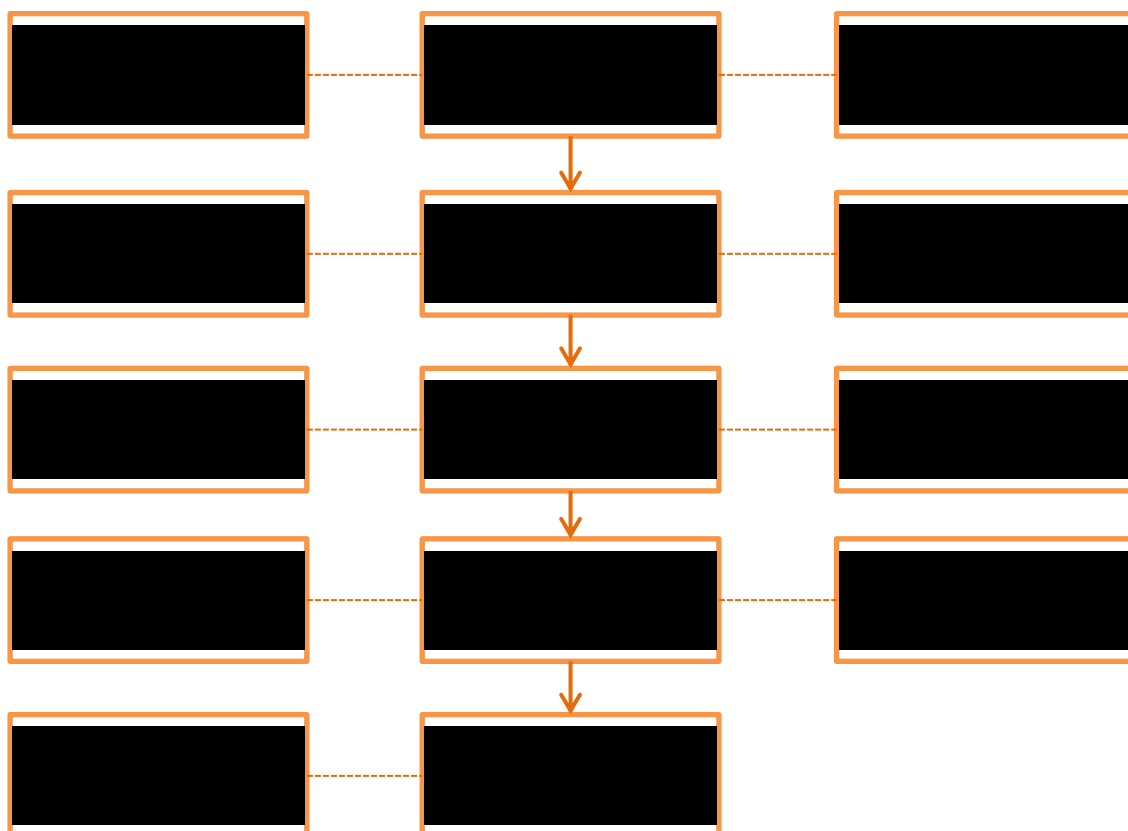
The focus of phenomenological research is to investigate the meanings made by individuals as a result of everyday lived experience, so it lends itself as a tool for researching phenomena in health and nursing fields (Balls, 2009). Health professionals must try to understand the experience of illness, disease and disability from the perspective of those living with it every dayⁱ. Balls (2009) describes how health researchers often choose phenomenological research

methods because they value the contribution and experience of the patient, “it considers the whole person and values their experience” (p.2).

The use of life grids in the literature

The research scaffolding, including the epistemological and ontological context of the study are shown in figure 1, a figure to show how the context leads to the methodological approach, interpretive phenomenological methodology, and from this to the methods – specifically life grids.

Figure 1. Diagram to show the research scaffolding of the study



Life grids are a fairly recent qualitative data collection tool that have been employed to gather retrospective data. They were first used by Gallie (1988), and then developed by Blane (1996), Berney and Blane (1997) and Holland, Berney, Blane and Davey-Smith, (1999). Originally, these researchers used life grids to facilitate the recall of historical information. This use was continued by researchers such as Edwards et al. (2006) who used life grids to investigate smoking behaviour over life spans; Wilson, Cunningham-Burley, Bancroft, Backett-Milburn and Masters (2007) who investigated the experiences of young people of parental substance misuse; and Haglund (2004), who also worked with younger participants and their recall of life events. Haglund (2004) claims that “the life history approach is well suited to a wide variety of types of health-related inquiry.....[and is] well suited for inquiry in a wide variety of psychosocial phenomena” (p. 1309). Life grids have therefore, been used as a retrospective way of reflecting on past experiences. When conducting life grids, researcher and participant(s) work on a large piece of paper, with a timeline down one side. Parry, Thomson and Fowkes (1999) suggest that to add key events to the timeline assists in the recall for participants. The interview then takes place around the time period outlined and as participants offer information this is mapped, usually by the researcher, on to the piece of paper. Parry et al. (1999) claim that this method is useful for several reasons;

1. that the use of the timeline and particularly adding key historical events facilitates recall of events.
2. that the mutually collaborative task of filling in the paper and giving an external focus to the interview can help facilitate the participant/researcher relationship.
3. that the task helps provide focussed information because the task is quite specific.
4. that it can help the discussion of difficult events because rather than being face to face with a researcher, the focus of the information is the paper in front of the researcher and the participant.

5. Because information is concrete and in front of the participant, they claim the participant has as much control as they feel comfortable with, over the data, and this redresses any researcher/participant power imbalance.

While many authors advocate the use of interviewing as a method for the elicitation of data, many do not provide technical information as to 'how to' interview. Life grids give a technical prop for the researcher because they are a concrete task for structuring interviews. A disadvantage discussed by Bell (2005) is that because life grids are retrospective, memories can be distorted and may not always be accurately recalled. They may become partial or biased accounts. It could however be argued that what is actually recalled is what is important. In studies such as ours accurate and detailed recall is not necessarily required, rather the 'essence' of the experience and meaning derived from the experience are what is important.

Wilson et al. (2007) used life grids to discuss young people's accounts of parental substance use. They supported the findings of Parry et al. (1999) in terms of the benefits of life grids, but they also found that life grids helped to represent the voice of the participants and placed their stories within everyday life. Wilson et al. (2007) felt that using life grids facilitated detailed data collection and that they reduced the need for lengthy interviews. Mattingly and Garro (1994) state that "through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped shape our history" (p. 771). This aligns with the proposition that meaning is produced in association with experience and meaning in turn is adapted and modified when applied to the next similar experience.

Data collection and use of life grids in this study

The primary data for the study were developed through semi structured interviews so the data were transcripts of these interviews, the researcher's field notes and reflective notes immediately following the interviews. The field notes helped provide context to the interview data, and the reflective notes assisted the researcher in learning and developing as a researcher, as well as providing context to assist with interpretation, and provide prompts for structuring future discussions with participants. The interview data, following transcription were analysed using Giorgi's (1997) five step mode, whereby

1. the verbal data were collected, recorded and transcribed by the researcher
2. The data were read by the researcher until it was familiar. The researcher also transcribed all the interviews to immerse in the data, to ensure familiarity and to begin stage
3. breaking down the data into broad related areas
4. organizing the data into themes
5. synthesising the data and preparing for presentation.

All this analysis was done by hand so that the researcher could stay physically close to the data, moving sections around until they fitted the subordinate and superordinate themes. As issues were discussed, following reflection on the sessions, and through the making of field notes, they were raised at subsequent interview sessions and clarified with the participants for further information or accuracy.

As the data were collected from participants in this study, a timeline approach emerged. Lifegrids were discussed during the data collection phase with the research team, and determined to be a potential tool for drawing together the data, given that they were developing in a chronological manner. As such lifegrids naturally lent themselves as a tool to facilitate interviewing and data collection that would fit with the way the participants were presenting data. Because data collection was already underway using unstructured and semi structured interview styles, life grids were then used at the end of the series of interviews with each participant. They were used to capture and summarize the key issues and events discussed, to map these in to a coherent timeline, to allow participants to reflect and accuracy check our understanding and interpretation of their data, to allow us to clarify any areas of uncertainty and to allow the participants to add further information they felt was missing. As Haglund (2004) states, the life grid is a process “incorporating the participants’ retrospective life experiences and the researcher’s interpretations” (p. 1309). Specifically in terms of member checking, in preparation, the researcher populated the life grids with key events mentioned during interviews, and with key themes pencilled in for discussion. We then conducted a summary interview where the participants directed what should be on the life grid, what was important for inclusion. The data on the lifegrids were discussed and negotiated between researcher and participant until both were happy that the superordinate themes were appropriate, that the key events had been recalled and interpreted correctly and that the representations made by the researcher were accurate. In this way the views of the 3 participants were determined, incorporated and represented in the lifegrids. Extensive analysis of the lifegrids was not required because in themselves they were a method of ensuring the accuracy of the analysis of the main body of data, and were the participants’ own summary of the interviews. They were taken on face value and used to support the interpretations of the data and the propositions of the study. The life grids were prepared as

per the descriptions in the existing literature - a large flip chart was prepared with a timeline down the left hand side. Key events that had been discussed in the interview sessions were mapped along the timeline. These were discussed again with the family members, in the context of the overarching aim of the study and the study questions, in order to clarify responses and meanings in relation to experiences.

Life grids and phenomenological research

Phenomenology requires methods that allow for in depth exploration of everyday experiences and meaning making. To this end either unstructured or guided interviews are often the method of choice (Smith et al., 2009). In this study the methods developed as follows. To allow the participants to tell their own stories, initially unstructured interviews were used. This allowed the participants to talk freely around their experiences in relation to their family member's dysphagia, food and mealtimes and to begin to explore around the overarching aim of the study. This follows the advice of Giorgi (1997) who claims that "when description and an interview are used together, the description usually comes first and is used as a basis for further elaboration during the interview" (p. 245). Following initial unstructured interviews an informal interview guide sheet was drafted (appendix 1) which focussed on themes and gave ideas for phenomenologically worded prompts related to the research questions, in order to focus the discussions in more detail, and ensure the research questions were addressed.

The interview guide sheet was used with all three participants in later interviews to ensure depth and comparability of data. A flexible approach with the guide sheet was used so not all guide questions and prompts were used if they weren't needed and the discussion was covering the appropriate areas. The guide sheet also listed suggestions for general prompt

phrases to use to drill further into the subjects the participants were discussing and encourage them to think about the meanings of their experiences.

Participants

The study described here examines the experiences of three mothers of adult children with PIMD and dysphagia:

- Mother 1 – a mother of a 24 year old man with PIMD. She has been a single parent since her son was approximately 3 days old. She used to be a professional musician. Since her son was born she has had admin jobs, but now works full time as a paid member of his home based care team. Her son receives his nutrition and hydration through a gastrostomy tube, which was placed at the age of 11. He receives some food and fluid orally for pleasure, particularly enjoying tiramisu. He has visual impairment, epilepsy, and is dependent on a wheelchair for all his mobility. He enjoys trips out to cafes and restaurants, loves watching cooking programs, listening to music and spending time with family and friends.
- Mother 2 – a mother of a 25 year old woman with PIMD and Rett Syndrome. She lives in a family unit with her husband, her daughter's father. They also have two adult sons who are married and have their own families. Grandchildren are regular visitors to the house. She used to work in a bank, but since her daughter was born has taken several jobs which fit in with her daughter's life, such as a night receptionist in a hotel, bar work and working in a supermarket. She now works full time as a paid member of her daughter's home based care team. Her daughter receives all her nutrition and hydration through a Jejunostomyⁱⁱ. Over time she has increasingly

refused oral intake and now receives nothing orally. She requires regular physiotherapy and is prone to recurrent chest infections. She has epilepsy and gastro-oesophageal reflux. She loves watching Disney DVDs, hydrotherapy and spending time with her family.

- Mother 3 – mother to a 40 year old woman with PIMD and Cri-du-chat syndrome. Her daughter passed away at the beginning of the study but mother 3 wanted to remain as a participant in the study. She lives with her husband, the father of her daughter. They have 4 other adult children who have their own families. Mother 3 worked throughout her daughter's life, until she retired, as a cook and chef. Her daughter attended a day centre 5 days a week. Members of their extended family visited the house for a few hours a day to help care for her daughter. Their daughter had ongoing difficulties maintaining adequate nutrition and hydration orally, but following discussions a gastrostomy was never felt to be appropriate to support her intake. Her daughter had epilepsy and was prone to chest infections. She used to love shuffling about the house on her bottom and particularly enjoyed spending time having cuddles from her Dad. She loved having things to eat and drink with her Mum.

Benefits of life grids used at the end of data collection

An important finding from this study is the utility and applicability of life grids used in way here that they have never described as being used before in the literature. They were found to be extremely useful in clarifying, organising and checking data with the participants. They also provided a visual representation of the sum of the important data, and acted as a tool to 'close' the data collection period with the participants. If we review the rationale for using

life grids proposed by Parry et al. (1999), but in the novel context of being used at the end of data collection, we can see the additional benefits they can bring.

1. Key historical events facilitate the recall of personal events

In the use of life grids as documented in the literature, where participants are asked to remember many years ago, researchers have used key historical events to help facilitate recall. So for example Berney and Blane (2003) describe life grids with events such as the General Strike in 1925, the outbreak of war in 1939 and the Suez Crisis in 1955 mapped down the left hand side to help the participants remember where they were living at that time, and their own key life events like marriages and deaths. In this study the use of key historical events was not as important as the key life events for the mothers, and how these facilitated recall of their experiences of food, mealtimes and supporting their children. We can see from extracts from the participants how personal life events were used in this way.

Mother 3's life grid begins with her life before her daughter. We recorded the jobs that she did which included working at a college in the kitchen and helping the home economics teachers. She also worked in a cake shop. We have then drawn a bubble which has the word 'identity' in the middle. From this come the words 'nurturing' and 'got to feed'.

We can see here how Mother 3 has linked key events from her own life, with discussion about her role as a mother, and her identity. This then supported further conversation about her identity since her daughter was born

Mother 1 has down the side of her timeline the point where her son is born. Before this she has words that describe her life, including 'musician', 'travelled world', 'cosmopolitan' and 'civil servant' – a job she did once her son was born. She then

has a circled statement that describes her stopping working when her son was 3 years old and coming from this are the words 'no life'.

Again like mother 3 we can see how Mother 1 has linked key events associated with her son, her working life and her identity. This again led to a lengthy discussion about how her identity as a mother was linked with how she planned and prepared food for her son, and fed him. She described how these activities were all consuming and she talks about how hard this work was.

2. *The mutually collaborative task of filling in the paper and giving an external focus to the interview can help facilitate the participant/researcher relationship.*

This was not so relevant in this study. The participant/researcher relationship had developed over the period of data collection and the life grids were used as an activity to cement and consolidate this work. That said, the task was a positive task to undertake. It felt mutually collaborative and the participants engaged enthusiastically with the task. They were able to reflect on the information presented, add and adapt information and even think in depth about the personal implications of the discussions we had had. They were able to develop new understandings about information that was reflected back to them.

Son 1 has tasters [small amounts of oral intake for pleasure when all other nutrition is via a gastrostomy tube], and they often happen outside of mealtimes, as a specific activity. Mother 1 had not recognised this until we discussed it during the life grid session. On their trips out Mother 1 and her son will chose a café they know to be suitable and they go there so that he can have his tasters. During the life grid session we were able to identify how Mother 1 views his tasters as a specific activity rather than this being part of everyday mealtimes. We discussed this and Mother 1 reported that this was the first time she had understood this. She was able to use the life grid

activity as an opportunity to discuss moving forward with the next step being to integrate her son's tasters in to mealtimes so they could eat together.

3. *Life grids help to provide focussed information because the task is quite specific.*

The issue of 'friends' was an area that wasn't discussed at length by the mothers during the interviews. On review of data during the process of analysis it became apparent that this was a gap. To this end, the life grids were used to probe about the relevance of friends to the lived experience of PIMD and dysphagia from the perspective of family carers.

Mother 1 was able to identify how friends had 'fallen by the wayside' when her son was born, and had not been a source of support for her. She reflected that she has since develop friendships with parents of have children who also have disabilities, and she has many friends at church. Mother 3 reflected that she also has many friends at church.

In terms of the themes that emerged during interviews, these were placed on the life grid templates before the session. In the life grid session mother 2 was able to explore some of the issues associated with wide relationships within the community. She talked about how they try to still ensure they have positive family experiences and weekends with family, which hadn't previously been discussed in the interviews.

4. *Help the discussion of difficult events*

While all the respondents were able to discuss some very difficult events, the life grids consolidated this information. We had mapped some of the key life events on the flip chart paper prior to the session. In many cases these key life events were often associated with stressful or difficult times for the mothers, children and families. During the life grid sessions in particular, some of the mothers did become upset. However, the focus of the task allowed

them to talk and acknowledge this and then move forward with the discussion. For example, during Mother 3's life grid session she became upset because sadly her daughter passed away at the very outset of this study. The life grid work obviously addressed this time, however, the focus of the continuing time line allowed Mother 3 to continue discussion:

In the discussion that took place during the life grid session Mother 3 indicated that since her daughter's death she had started to volunteer on an evening for the Gateway club – a youth club for adults with learning disabilities.

In the session with Mother 2, she was able to discuss the point of diagnosis of Rett Syndrome for her daughter. She described how her concerns weren't listened to early in her daughter's life, how the diagnosis was a shock, and how she went in to denial about the diagnosis.

5. *Data are concrete and visible in front of the participant, therefore giving the participant as much control as they feel comfortable with*

All the mothers appeared satisfied with the information as it was presented and developed throughout the life grids session. In particular the presentation of the life events in a timeline then helped us to reflect on their identities in a way that the mothers were in control of, and could direct and correct our understandings.

All the mothers talked about how their own identities are to a large part defined by them being Mum to their disabled child with dysphagia. This was often at the expense of other aspects of their identity. Mother 1 sums this up well. She describes how she became to be known, not as a person in her own right, but as her son's Mum, and she splits her life when she talks, into 'Pre-J' and 'Post-J'. When I talked to her about her

identity she says - “oh I lost that many years ago, I lost my name, I just became a label – Oh that’s J’s Mum”

During the construction of the life grid I asked her about identity. She talked about being a musician before Jack, travelling the world, having a cosmopolitan life with cosmopolitan tastes, and particularly describing an event in Spain where she had gone in to the countryside and eaten traditional Spanish food with an elderly peasant lady. When I asked her about after Jack there is a note on the life grid that says “3 years old, stopped working, no life”. She talked then about her identity as being a mother to J and the associated notes here say “fed him, prepared for him, plan for him, cooked batches of meals”.

Mother 2’s life grid shows that her identity before her daughter, although a mother to two boys at this time, was linked to her job in the bank. The life grid, at the point that her daughter is born states “identity = mother”.

Throughout her daughters’ life Mother 3 always worked as a cook, in nursing homes and then in a monastery. This is interesting to note, in that she always cooked for other people and nurtured others via the provision of food, as well as focussing on the need for food for her daughter. Mother 3 herself confirmed in the life grid discussion that her experience of mothering has been characterised by food.

One of the disadvantages discussed in the literature regarding lifegrids is the issue of hazy recall of events, if events took place some time ago. For this study this was not felt to be a relevant disadvantage. The accurate recall of events in date order was not necessary to understanding the lived experience. More important were the feelings, beliefs, and meaning

making associated with the experience and as such life grids were a relevant and appropriate tool.

Conclusion

In conclusion, this study proposes the novel use of life grids as a useful tool for concluding the data collection phase of a study. Previously life grids have been used at the outset of a study to help facilitate the development of the participant and researcher relationship, to facilitate recall of information, to help discuss difficult and emotive topics and as an activity which puts the participant in control. While life grids used in the novel way described in our study had the positive attributes listed in previous studies they also had the benefits of acting as a member check, so findings were clarified, any remaining gaps in the data were filled and any remaining inconsistencies were further discussed and investigated. These member checks served the function of checking our understandings and interpretations of the information. Together we were able to clarify and organise the data, and this activity gave the participants a visual representation of the sum of their data. Finally an important benefit of using life grids at the end of the study meant that they acted as a tool to ‘close’ the data collection period with the participants, and provided a positive activity with which to withdraw from the field. We recommend use of the life grids in this manner so that their utility can be further examined and reported to the benefit of the field of qualitative research.

The authors declare that there is no conflict of interest.

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ⁱ It is increasingly important, particularly with recent policy drivers such as the inquiry in to the failings at Mid Staffordshire Foundation Trust (Francis, 2013) and the response to the events at Winterbourne View (DoH, 2012), to work alongside patients, and to listen to patient voices.

ⁱⁱ A tube placed in to the small intestine to deliver nutrition, hydration and medication